Ethical Issues in Collaboration: Staying Evidence-Based While Working with Other Disciplines

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Collaboration

- To work, one with another
- To work jointly with others, especially in an intellectual endeavor
Synonyms

• Teamwork
• Partnership
• Working together
Why is it important in ABA?

• We are committed to maximal change
  – Ineffective treatments abound
  – Most learners receive a combination of evidence based and non evidence based interventions
Why else?

• We operate in interdisciplinary teams
  – Different levels of evidence
  – Different definitions of EBP
  – Different worldviews
Factors making it imperative that we identify effective treatments

• Wasted time leads to poorer outcomes
• We must identify empirically supported treatments and develop consensus on evidence-based practice
The interpersonal challenge
We do not know everything

- Everyone you will ever meet knows something you don't.

- Respect is not imposed nor begged. It's earned and offered.
Basic respect can be observed

Respect Words

- Respect
- Courtesy
- Tolerance
- Appreciation
- Acceptance
- Consideration
- Patience
- Attentiveness
- Manners
- Politeness
Broaden our lens

• Professionalism

• Collaboration as a verb and as a process
Now, how we do work together in the context of EBP
What do we share in common?

• Value on positive work environment
• Desire for respect
• BEST INTERESTS OF THE LEARNER
Challenges within *autism treatment*

- Claims abound
- Consumers are confused
Criteria to define evidence as meeting EBP

- Sources that publish criteria for what constitutes evidence:
  - American Psychological Policy Statement
  - Chambless, et al. 1996
  - Chambless & Hollon, 1998
  - U.S. Department of Education
  - Presidential Task Force on EBP
  - Sackett, et al., 1996
  - U.S. Department of Health
  - Horner, et al., 2005
  - IDEA
Organizations that Support the Concept of EBP

- U.S. Department of Education
- Health Resources Commission
- U.S. Department of Health and Human Services
- National Alliance on Mental Illness
- Agency for Healthcare Research and Quality
- National Resource Council
- ABAI
- BACB
- APBA
Standards for Effective Treatment

- Chambless, et al. (1998)
  - Similar positive effects demonstrated by multiple researchers
  - Clear specification of intervention details in manuals
  - Several replication studies involving 10 or more subjects

- New York State Health Department (1999)
  - Multiple studies by multiple investigators
  - Use of experimental designs
  - Controls for bias
Definition of EBP

A body of scientific research shows that the practice has **specific** effects that are **replicated** independently.
Definition of EBP

* Based upon research that involves objective procedures to obtain reliable and valid knowledge
Criteria for Judging the Quality of Evidence

- multiple studies done by multiple investigators
- use of experimental designs
- controls for bias
- reliability of measurement
- operational definition of terms
- objective data
Criteria for Judging the Quality of Evidence

- control for internal and external validity threats
- identification of independent and dependent variables
- several replication studies, using designs
- replication studies involving 10+ subjects
Why we should know about EBP

• The field is constantly changing.
• Procedures move up or down the ladder of empirical support (e.g., PECS).
• Our decisions about treatment should be influenced by these categorizations.
Some things that make it hard to navigate the treatment world

- Everyone says they are evidence based
- Everyone says they have data
- We need trusted resources
Where do these dilemmas arise?

• Parents face critical decisions about intervention
• Parents are inundated with information
• All data are not equal
• Even professionals can have difficulty evaluating quality of evidence
Where else do these dilemmas arise?

• In treatment teams............
Let’s examine an historic treatment trend

• Facilitated communication
  – Tremendously destructive
  – Based on beliefs vs. reality
  – Resulted in egregious violations of individuals’ and families’ lives
Statement on Facilitated Communication, 1995

ABAI
• A technique, known as Facilitated Communication (FC), has been promoted and disseminated as a method for “revealing” undisclosed intellectual competence in persons diagnosed with autism, moderate to profound mental retardation, or other disabilities.

• FC is a technique wherein a facilitator touches the hand, arm, or shoulder of a person with communication deficits while they jointly point to symbols, letters, or words.
ABAI Position Statement

• Claims have been made that this technique permits many people with severe disabilities to communicate at levels far exceeding those demonstrated by any other means.

• These claims have been based on descriptive and qualitative reports or personal accounts. Numerous peer-reviewed scientific evaluations, however, indicate clearly and compellingly that FC does not allow persons diagnosed with disabilities to communicate at enhanced levels.

• The source of apparent communication is the facilitator, although most facilitators report that they are not aware that they are the source.
To date, there is no objective, scientifically sound evidence that FC has any direct therapeutic benefit. The use of FC to “communicate” entails serious risks, including:

1) Violating the rights of people with disabilities to autonomy, privacy, genuine self-expression, self-determination, protection from experimentation without informed consent, and appropriate education and treatment;
2) Promoting dependence rather than independence in people with disabilities;

3) Misusing human and material resources that could be better spent on other interventions, e.g., time spend employing FC interferes with the use of communication systems that have a scientifically documented history of success;
4) Fostering expectations about people with disabilities that are unlikely to be realized;

5) Taking actions related to medical or other treatments, living and work arrangements, personal relationships, test and classroom performance, and other decisions about people with disabilities without objective verification that the communications represent their own wishes and competencies;
6) Promulgating false allegations of abuse and mistreatment, resulting in emotional distress and unnecessary legal and financial difficulties for many people with disabilities, their families and others. Thus the use of FC directly threatens the human and civil rights of the person whose communication is purportedly “facilitated,” and may also jeopardize the rights of others.
Autism, mental retardation, and other disabilities can result in diverse and often marked deleterious effects on adaptive behavioral development and communication skills. Parents and other caregivers of persons manifesting these conditions consequently are highly motivated to seek and obtain service that offers any promise of being effective in ameliorating these conditions. As a result, such caregivers are vulnerable to those who promote ineffective methods.
FC is not to be confused with use of appropriately applied manual guidance or other prompts to teach communications and other skills, nor should it be confused with independent use of nonspeech communication systems that may involve letterboards, keyboards, or other symbol systems.
It is the position of the Association for Behavior Analysis that FC is a discredited technique. Because of the absence of ample, objective, scientific evidence that FC is beneficial and that identifies the specific conditions under which it may be used with benefit, its use is unwarranted and unethical.
A task force authorized by the Executive Council of the Association for Behavior Analysis generated the above statement concerning the technique called Facilitated Communication (FC). Members of the task force independently reviewed the scientific literature concerning FC and agreed unanimously to the content of the statement. The Executive Council unanimously approved the statement in 1995, and it is the official position of the Association for Behavior Analysis.
And yet, FC persists

• Several years ago, an Oscar was awarded to an independent film that focused on FC

• It remains an intervention that is sought

• Various permutations of it also abound
What Characterizes Fad Treatments?

- No empirical proof of effectiveness
- At times, empirical proof of ineffectiveness
- Wildly popular
- Associated with great promise/hope
Why Do Fad Treatments Persist?

• What might contribute?
• NEED FOR HOPE
• APPARENT EASE OF INTERVENTION
• EMOTIONAL APPEAL
Anti-science and Pseudo-Science

**CORRELATION VS CAUSATION**

- Anecdotal reports
- Absence of research design
- Sometimes a disinclination toward objective verification/scientific inquiry (anti-science)
  - Belief as an important variable
  - Claims of universal significance
  - Scientific scrutiny devalued
Pseudoscience

A way of investigating the world that seems to adhere to basic scientific methodology BUT DOES NOT

• Uses technical jargon
• May reference known scientific content
Anti-Science

- Belief as a variable
- Rejection of empirical verification attempts
- Circular reasoning about untestability
- Universal appeal and actually unexplainable
How to Minimize Adoption of Fad Treatments

• HOW CAN WE INSULATE CONSUMERS AND PROFESSIONALS AGAINST THESE INTERVENTIONS?
Science/Applied Behavior Analysis

- CORRELATION VS. CAUSATION
- Rule out alternative explanations

FIND THE CONTROLLING VARIABLES
What constitutes science?

Science

- Is it objectively demonstrated?
- Has it been replicated?
- Is it valid?
  - Internal validity: not due to other variables?
  - External validity: generalizable?
Good research

• Well designed procedures
• Designed well
• Controls for other variables
• **Reliable** measurement
How does EBP influence decisions on treatment in autism?

• BCBA’s and non-behavioral treatment

• Most BCBA’s will work in team contexts in which clients are receiving a combination of evidence-based and non-evidence based interventions

• What is our obligation in these contexts??
Examples

- A BCBA is approached by a former client, who says that the child’s current teacher has recommended AIT. She is hopeful that the long-standing processing problems might be addressed through this intervention. She asks what the BCBA knows of it/thinks about it.

- A parent of a child with autism says at the annual IEP meeting that she is finally going to try the gluten free diet. She recently saw Jenny McCarthy on a talk show, and she wants to see what happens for her son on the diet.
Examples

• A parent has asked that the school program do rapid prompting/SOMA with their child. They have hired an out of state consultant to come on a regular basis. The school was invited to a session, which the BCBA attended. The BCBA became very concerned on many levels about the nature of the intervention, and about the appropriateness of the content taught. She saw an adolescent with severe issues in every area of functioning being prompted to respond to material about the Bushmen of the Kalahari and the Lewis and Clark Expedition. She believes the responses are almost entirely the result of over-prompting and inadvertent prompting. She has been asked to find a way to incorporate the intervention into the school program. What should she do?
What guidelines help us navigate these challenges?

- There are several guidelines that assist us here
- Focused on effectiveness and our commitment to effective intervention
- Focused on our obligation to evaluate tx impact
Section 2.09

• 2.09 Treatment Efficacy.

• (a) Clients have a right to effective treatment (i.e., based on the research literature and adapted to the individual client). Behavior analysts always have the obligation to advocate for and educate the client about scientifically supported, most-effective treatment procedures. Effective treatment procedures have been validated as having both long-term and short-term benefits to clients and society.

• (b) Behavior analysts have the responsibility to advocate for the appropriate amount and level of service provision and oversight required to meet the defined behavior-change program goals.
(c) In those instances where more than one scientifically supported treatment has been established, additional factors may be considered in selecting interventions, including, but not limited to, efficiency and cost-effectiveness, risks and side-effects of the interventions, client preference, and practitioner experience and training.

(d) Behavior analysts review and appraise the effects of any treatments about which they are aware that might impact the goals of the behavior-change program, and their possible impact on the behavior-change program, to the extent possible.
And related parts of the code

- 7.0 The Behavior Analyst’s Responsibility to Colleagues.
  - Behavior analysts have an obligation to bring attention to and resolve ethical violations by colleagues.
What can be done?

- Education of the team (ALWAYS)
- Creation of a single case design to evaluate the impact of the intervention at the level of the individual (SOMETIMES)
  - WHEN is it yes?
  - When is it no?
Let’s revisit the ethical dilemmas posed

- Auditory Integration Training

- What about effectiveness?
  - Lacks empirical basis; no supporting data
  - ASHA has a position statement against it
  - AAP has a position statement on its ineffectiveness
  - Would you evaluate at level of individual? NO
Let’s revisit the ethical dilemmas posed

• Rapid Prompting
• What about effectiveness?
  – Lacks empirical basis; no supporting data
  – Must educate the team
  – Similar to FC
  – Pseudo- science? Anti-science?
    • Belief as a variable
    • Not a teachable technology
  – Evaluate at level of individual? No
Let’s revisit the ethical scenarios

- Gluten free diet
- Ineffectiveness should be discussed
- Risks should be discussed with parents
  - Nutritional deficiencies
- Medical input should be sought
- If there may be food sensitivity or allergy issues that are medically confirmed, it could be methodically tracked
- Evaluate impact? MAYBE IN VERY SPECIFIC SITUATIONS WITH MEDICAL COLLABORATION
Bottom line

• Some procedures should not be investigated (red lights)
  – Evidence of harm (e.g., FC, Chelation)
  – Documented, clear no effect
  – Position statements exist against them
  – Anti-science (belief as an important variable, guru-based)
• Some not yet empirically validated procedures (yellow lights) might be explored with data when
  – Operational definitions are agreed upon and a data collection system is put in place AND
  – Team agrees to a data-driven ultimate decision on continuance
Bottom line

• Families will pursue these interventions

• We can serve a useful function in helping to make a data-based decision on continuance.........

• First line of influence should be education of the team
  – May remove need for evaluation at level of individual and save this time
How do we decide where our comfort is with non evidence-based procedures?

• Rely on science
  – Do not pursue red light procedures
• Make a data-based evaluation of impact if you intervene with the method
• Alter/continue/discontinue based on data
What is the main mechanism for studying effect?
An individualized systematic assessment of the intervention as it applies to this individual.

Behavior analysts can assist in this.

- experimental designs
- operational definitions
- measurement systems
- treatment integrity
- graphing and analysis of data
If you pursue an unproven treatment.....

• Objectively examine the impact of the treatment in a way that facilitates a data-based decision about the impact

• Listen to the data - let the data determine
Many of us work in non-behavioral worlds

• We may be able to shape these environments
• We may be able to shape these colleagues
• Some sections of the Code encourage us to do exactly that
  – Provide the behavioral view
  – Educate others about science, pseudo-science, and anti-science
  – Help others understand levels of evidence and the concept of EBP
  – Encourage data based decision making at the level of the individual
“It is ok to be open minded, as long as your mind is not so open that your brains fall out.”

Carl Sagan
Dr. Sandra Harris

- “Let the data speak!!”
For more information.....

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